

Statement of Representative Edward J. Markey (D-MA)
Introduction of the Stop Taking Our Health Privacy (STOHP) Act
October 16, 2002

When you visit your physician, do you know where your medical records are kept? Do you know how your private health information is being used? Do you know who is disclosing your sensitive medical files, to whom, and for what purposes?

These questions have become increasingly urgent for the majority of Americans. According to a recent Gallup Survey, 78 percent of people in the United States believe it is very important that their medical records be kept confidential. But the time has long passed when patients could feel confident that their medical files were locked safely in the office of the family doctor, protected from prying eyes and unauthorized access. Today, interconnected computer networks link your health provider, health plan and various corporate intermediaries such as "health care clearinghouses," that methodically translate your personal health information into digital bits and bytes to track and store your records in databases over which you have little control.

Consumers are particularly concerned about the unauthorized use of their private health information for marketing purposes. That's because companies have exploited patients' sensitive medical records in pursuit of profits. For example:

- The chain drug store Eckard's used the signatures obtained by customers when they picked up their prescriptions as authorization to release their information for marketing purposes. Eckard's eventually settled with the Florida Attorney General's office and agreed to require patients to opt-in before their information can be used for marketing.
- Several Florida residents received unsolicited samples of Prozac in the mail from a drugstore. A recipient of the Prozac mailing sued her doctor, pharmacy and the drug company for violating her privacy.

Fear of private health information falling into the wrong hands has replaced faith in the confidentiality of personal medical records.

A report by Princeton Survey Research Associates indicates that 1 in 6 people in the United States has done something out of the ordinary to keep personal health information confidential, including withholding information from their doctor, providing inaccurate information, or, in some cases, avoiding care entirely.

A "stress test" should not refer to your ability to withstand anxiety over the vulnerability of your medical records.

This summer, the Department of Health and Human Services confirmed consumers' worst fears about threats to the confidentiality of their health information when it stripped away key privacy protections established during the Clinton Administration. By modifying the Privacy Rule finalized in December 2000, HHS eliminated your right to decide whether your medical information can be shared for the purpose of health care treatment, payment, and so-called "health care operations." These modifications took effect on October 15th.

In the case of treatment, payment and health care operations, the Bush Administration's modifications permit your medical secrets to be used and disclosed to doctors, pharmacists, health insurers, and others without your prior consent.

While treatment and payment are terms that consumers understand and associate with health care, "health care operations" is a category tied closely to commerce, not patient care. In fact, the Bush Administration modifications make clear that health care operations is a vast category that has more to do with business mergers than better medicines:

According to Section 164.501 of the Bush modifications, health care operations means:

"The sale, transfer, merger, or consolidation of all or part of the covered entity with another covered entity, or an entity that following such activity will become a covered entity and due diligence related to such activity."

It is understood that this category includes business planning, underwriting, fundraising, and other activities. This means that your private health information can be used without your permission to serve the commercial interests of health care companies, including during transactions such as the sale of an HMO. The Clinton Administration's definition of health care operations not only was narrower, but it also required patient consent before personal health information could be used and disclosed for this purpose.

The Stop Taking Our Health Privacy, or "STOHP", Act puts patients' privacy first by closing massive "privacy peepholes" that HHS opened in these three key areas:

1. **Consent:** The STOHP Act restores the right of patients to decide whether or not to permit the use and disclosure of their personal health information for purposes of health care treatment, payment and "health care operations". The STOHP Act includes commonsense exceptions to the consent requirement for such purposes as filling a prescription and making referrals. In August, HHS eliminated patient consent in these three important cases, denying patients the fundamental right to decide for themselves whether to share their private health information.
2. **Marketing:** The STOHP Act ensures that pharmacists do not become secret agents for drug companies. When you receive treatment recommendations from your pharmacist, you should not have to wonder who stands to benefit more: you or the pharmacist or drug company. Our bill would reverse the change that HHS made to the marketing definition, which allows health providers to send unsolicited health recommendations to patients that are paid for by drug companies but do not inform patients of the pharmacist's financial incentives or provide patients the opportunity to opt-out of receiving such communications in the future.
3. **Disclosures to FDA-regulated entities like drug companies:** The STOHP Act narrows the purposes for which personal medical information can be used or disclosed to these entities without patient consent. Our bill limits nonconsensual disclosure to these entities for the purpose of strict public health priorities such as drug recalls. The August modifications created a broader exemption that allows

nonconsensual disclosure of patient information to drug companies for a wide range of activities, which may include marketing campaigns.

I am pleased to be joined by my colleagues Representatives Dingell, Waxman, Berman and Capuano as we introduce the Stop Taking Our Health Privacy Act of 2002.

Today we take steps to apply age-old principles of medical privacy to the realities of the information age. Today we seek to restore longstanding patient protections, ensure the confidentiality of the physician-patient relationship, and rebuild patient trust in the health care system, all of which are essential for the delivery of quality, thorough health care.

Thank you.